

Trustees' Annual Report for the period

From	Period start date			Period end date	Day	Month	Year
	Day	Month	Year				
	01	January	2024		31	December	2024

b. Section A details

Reference and administration

Charity name

Pitt Hopkins UK

Other names charity is known by

Registered charity number (if any)

1167153

Charity's principal address

76 Auckland Road

Ilford

Essex IG1 4SF

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Sue Routledge	Chair		
2	Brian Routledge			
3	Leanne Groves			
4	Julie Cooper			
5	Melissa Stewart			
6	Maryrose Brennan			
7	Graham Fiveash	Treasurer		
8	Mark Haywood		15/1/2024	
9	Debbie Bromley		15/1/2024	
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				

20				
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Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

b. Type of adviser Name Address

c.		
d.		
e.		
f.		

Name of chief executive or names of senior staff members (Optional information)

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b. Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	Written constitution
How the charity is constituted (eg. trust, association, company)	CIO
Trustee selection methods (eg. appointed by, elected by)	Appointed by trustees

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

Trustee Face to Face meeting held in. April 2024 (see Section D)

Summary of the objects of the charity set out in its governing document

1. Raising awareness of Pitt-Hopkins syndrome for the public.
2. Supporting families by providing information and funding to facilitate opportunities to meet.
3. Making contact with medical and social professionals.
4. Encouraging research

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

Continuing support of research by Dr. Simone Mesman, Amsterdam.

Ongoing maintenance of mobile phone app.

Creation of new Pitt Hopkins UK website.

Participation as an elected patient advocate in the ePAG (patient advocacy group) for ERN (European Reference Network) ITHACA

Working with medical professionals with the Patient Led Research Hub (PLRH) in Cambridge.

Taking part in on-going free training on running a small charity online and in-person.

Pitt Hopkins UK represented at various meetings and events e.g. Genetic Alliance UK monthly online meeting, response to Downs Syndrome Act. etc

Improvement of charity governance.

All activities have been undertaken with due regard to the guidance issued to trustees by the Charity Commission on public benefit.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

Pitt-Hopkins mobile phone app management provided by a volunteer.

Ongoing redesign of the website has been provided pro bono by one of the trustees.

Nathan Routledge acted as a scientific advisor.

Summary of the main achievements of the charity during the year

Raising Awareness/Support

The charity continued to disseminate information and provide support to parents and families via dedicated support groups (Google, Facebook), Skype phone line, website, app, social media, e-mail and personal contacts.

The trustees explored the possibility of organising a weekend for families through the Barretstown residential centre in Ireland or at a Horse Riding Centre for the Disabled in North Wales. Further discussions about facilities and dates (2025) are ongoing.

An informal gathering, arranged at short notice, of some families took place in Solihull in October 2024.

A collage for Pitt-Hopkins Awareness Day (18th September) was constructed for use online.

The Charity continued to work with the Cambridge Rare Disease Network (CRDN), Beacon, EURORDIS, Genetic Alliance UK. Canva and Rare Revolutionaries and other relevant groups.

Doctors at Amsterdam Medical Centre were contacted via email for help about questions and information wanted by parents.

Working with medical professionals with the Patient Led Research Hub (PLRH) in Cambridge.

Two trustees took part in the parliamentary lobbies on Rare Disease Day (28/02/24) at Westminster and Edinburgh.

A player at Irchester United FC was sponsored by a parent to raise awareness of Pitt-Hopkins syndrome.

Administration

Mark Haywood and Debbie Bromley joined as trustees in January.

The trustees met five times during the year, four meetings being held on-line and a face-to-face meeting was held in April 2024 in Rochester, Kent. The AGM was held (on-line) in December 2024.

The charity policy on finance was reviewed and agreed.

The Chair, as an ePAG advocate and an elected member of the patient board for ERN ITHACA attended board meetings and participated in online training courses.

The free Pitt Hopkins UK mobile app was reviewed and design of the new website continued.

A pop-up tent and small PA system were bought for use at family gatherings

Finance/Fundraising

The income stream in 2024 came from individual donations, grants and Facebook and Give As You Live re-imbursements generated by numerous fundraising efforts e.g. Manchester 10K, Wing Walking and a mother in Ireland who climbed 40 peaks in Ireland. Funds were also generated from sales of T-shirts.

A new savings account with HSBC was opened and funds transferred.

The funding platform Wonderful was trialled.

It was agreed to investigate how to set up a lottery in aid of the charity.

Research

The Amsterdam research group contacted the charity to say that the 2023 report of the research progress would be sent in January/Early 2024. The final payment of the contract will be paid in early 2025.

Ongoing work with the PLRH on the anonymised data from the family registry which was launched in 2021. Meetings with medical professionals and researchers who are experts in Rett syndrome which can be a differential diagnosis to PTHS looking at how we can apply for funding for research into the breathing anomalies.

A statistician was helping analyse data held by the charity.

Notes on Trustee Face to Face meeting, April 2024, Rochester, Kent

Discussion on

- a) use of social media
- b) identifying geographical location, by postcode, of families to aid in organising local events and connecting families.
- c) re-assessing fund raising platforms used in view of high fees charged.
- d) ideas for use of accumulated funds
- e) merchandising of items from Simply Logo.
- f) succession planning and search for new trustees.
- g) demonstration of planned new website.

Section E Financial review

Brief statement of the charity's policy on reserves

£5000 held as reserve

Details of any funds materially in deficit

None

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

c. Section F

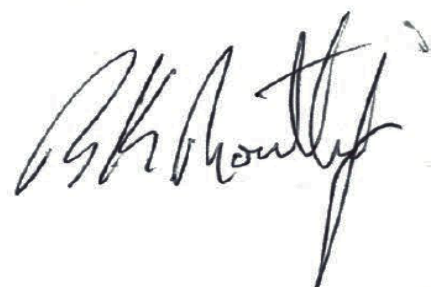
Other optional information

Section G Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)

Full name(s)

Susan Routledge

Brian Keith Routledge

Position (eg Secretary, Chair, etc)	Chair	Trustee
Date	11 th October 2025	11 ^h October 2025

Pitt Hopkins UK
Final Income & Expenditure Comparison Statement
January to December 2024

Donations & Income	Jan to Dec 2024	Jan to Dec 2023
4020 - Facebook	£1,308.14	£779.41
4030 - Give As You Live	£18,959.23	£6,444.84
4040 - Gift Aid	£2,128.73	£5,197.09
4050 - Mirren Thompson	£240.00	£240.00
4060 - Stripe	£5,869.44	£0.00
4045 - Wonderful	£2,010.00	£0.00
4070 - Amazon Smile	£0.00	£112.50
4090 - Other Donations	£3,834.97	£5,095.18
4900 - Other income	£122.53	£46.25
Total Income	£34,473.04	£17,915.27
Direct Expenses		
5025 - University of Amsterdam	£5,017.00	£0.00
5030 - Cost of PTHS Tee Shirts	£0.00	£90.00
5060 - PTHS Sponsored Events	£420.00	£220.00
5070 - PTHS Sponsored Family Meeting Events	£758.79	£0.00
5500 - Marketing	£627.93	£62.47
5600 - Conference Expenses	£1,577.82	£114.32
Total Direct Expenses	£8,401.54	£486.79
GROSS INCOME / LOSS	£26,071.50	£17,428.48
Expenditure - Overheads		
7050 -Other Expenses	£15.00	£0.00
7400 - Travelling	£249.45	£222.97
7420 - Trustee Expenses	£1,768.58	£150.00
7500 - Printing	£0.00	£74.99
7510 - Postage and Carriage	£8.15	£21.68
7530 - Telephone	£202.32	£202.32
7540 - Web Site Hosting & Development	£66.00	£275.03
7550 - Computer & Software	£2,528.33	£153.98
7620 - Consultancy & Professional Fees	£210.00	£385.00
7630 - Business Insurance	£284.39	£273.18
7900 - Bank Charges and Interest	£144.55	£88.31
8010- Office Equipment & IT Depreciation	£29.99	£0.00
8210 - Subscriptions	£234.20	£135.00
Total Overheads	£5,740.96	£1,982.46
NET INCOME / LOSS	£20,330.54	£15,446.02

* see note 1

*see note 2

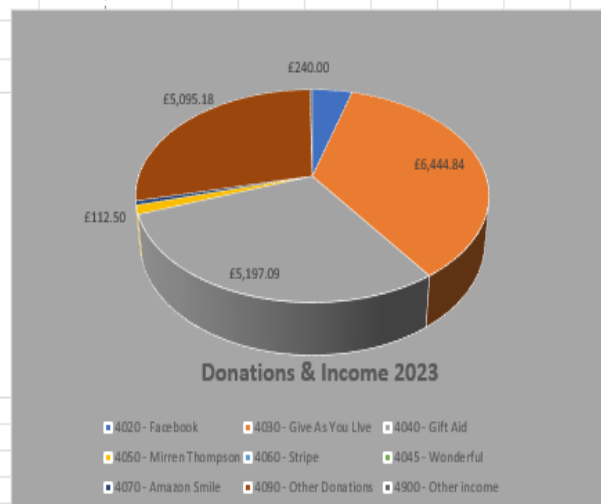
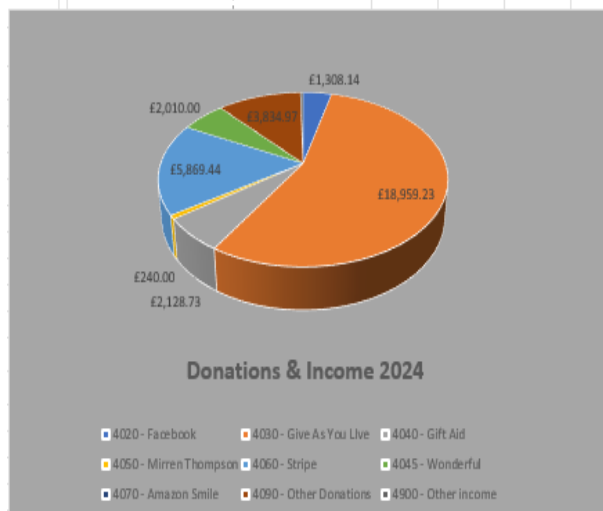
* see note 3

*see note 4

*see note 5

* see note 6

*see note 7



- Note 1** - The 2024 figures include the first donations made through the Wonderful which is free donation website i.e. No Payment or Admin fees
- Note 2** - The 2024 figures includes: E.Harrison donation of £600, 4 unnamed cheques for £328.46, £629.36, £519.62 & 226.00 plus a £500 Grant that Neil Burling arranged,
- Note 3** - The 2024 figures now include the final payment to University of Amsterdam for Research under the existing contract dated 20/6/2020.
- Note 4** -The 2024 figures include the costs for the Solihull PTHS Family Meeting Day in October 2024.
- Note 5** - The 2024 figures now include all travelling costs and entrance fees incurred by Trustees attending conferences that have previously been approved by the Charity.
- Note 6** - The 2024 figures include the cost of Trustees attending the annual face to face meeting in April 2024 that took place in Rochester.
- Note 7** - The 2024 figures include two annual subscription charges (2023 & 2024) for TextHelp software @ £1091 per annum.

Pitt Hopkins UK		
Finalised Assets & Liabilities Statement		
To 31st December 2024		
ASSETS		
Fixed Assets		
	Total Fixed Assets	£0.00
Current Assets		
1200 - Pitt Hopkins UK	49,608.10	
1230 - Nationwide 45 Day Saver	66,854.00	
1240 - Nationwide Instant Access Account	5,096.58	
*Interest Receivable	1,679.72	
	Total Current Assets	£123,238.40
	TOTAL ASSETS	£123,238.40
LIABILITIES		
Current Liabilities		
Future Liabilities		
	Total Future Liabilities	£0.00
	TOTAL LIABILITIES	£0.00
	TOTAL NET ASSETS	£123,238.40

*** Note: This represents 9 months interest (APR to DEC 2024) on the £66,854.00 that has been earned on the Nationwide 45 Day Saver Account.**

Pitt Hopkins UK
PROPOSED BUDGET

January to December 2025

Income	Jan to Dec 2025
Donations	£12,000
4040 - Gift Aid	£2,000
4110 - Interest Earned	£2,000
4120 - Tee Shirt Income	£0
Budgetted Income	£16,000
Direct Expenses	Jan to Dec 2025
5060 - PTHS Sponsored Events	£500.00
5070 - PTHS Sponsored Family Meeting Events	£1,000.00
5500 - Marketing	£600.00
5600 - Conference Expenses	£1,600.00
Budgetted Direct Expenses	£3,700
Overheads	Jan to Dec 2025
7400 - Travelling	£250
7420 - Trustee Expenses	£1,800
7500 - Printing	£100
7510 - Postage and Carriage	£200
7530 - Telephone	£100
7540 - Web Site Hosting & Development	£1,500
7550 - Computer & Software	£200
7620 - Consultancy & Professional Fees	£300
7630 - Business Insurance	£300
7900 - Bank Charges and Interest	£150
8210 - Subscriptions	£200
Budgetted Overheads	£5,100



Section A

Independent Examiner's Report

Report to the trustees/
members of

Charity Name
Pitt Hopkins UK

On accounts for the year
ended

Dec 31 2024

Charity no
(if any)

1167153

Set out on pages

1-4 of the accompanying document

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31/12/2024**

Responsibilities and
basis of report

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent
examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention (other than that disclosed below *) in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

** Please delete the words in the brackets if they do not apply.*

Signed:

Date: 16/4/25

Name:

Michael Waters

Relevant professional
qualification(s) or body
(if any):

C.Eng., FIMMM

Address:

22 Willowmead Drive, Prestbury SK10 4BU

Only complete if the examiner needs to highlight matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

For administration reasons, the deposit accounts only show the balance as at 31/3/2024.